# 5 WHAT IS PALLIATIVE CARE

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## What is palliative care?

*[Note: this is also the opening section of the IAHPC Manual of Palliative Care available in https://hospicecare.com/what-we-do/publications/manuals-guidelines-books/manual-of-palliative-care/]*

Palliative care is the care of patients with active, progressive, far-advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life.

The following should be noted:

- **active disease:** this activity can be confirmed and measured objectively by clinical examination and investigations;
- **progressive disease:** this too can be assessed clinically;
- **far-advanced disease:** more difficult to define but examples are extensive metastatic disease in cancer, refractory cardiac, renal or respiratory failure and total dependency in neurodegenerative conditions or Alzheimer's Disease;
- focus on the **quality of life** is the key feature of the definition
- it is **person-oriented**, not disease-oriented;
- it is **not primarily concerned with life prolongation** (nor with life shortening);
- it is **not primarily concerned with producing long term disease remission;**
- it is **holistic** in approach and aims to address all the patient's problems, both physical and psychosocial;
- it uses a **multidisciplinary or inter professional approach** involving doctors, nurses and allied health personnel to cover all aspects of care;
- it is dedicated to the **quality of whatever life remains for the patient**
- palliative care is appropriate for **all patients** with active, progressive, far-advanced disease and not just patients with cancer;
- palliative care is appropriate for patients receiving continuing "active" therapy for their underlying disease.

Palliative care should never be withheld until such time that all "active" treatment regimens for the underlying disease have been exhausted.

The message of palliative care is that whatever the disease, however advanced it is, whatever treatments have already been given, there is always something which can be done to improve the quality of life remaining to the patient.

## World Health Organization definition

**"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."**

### Palliative care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

This definition is available in http://www.who.int/cancer/palliative/definition/en/

## Types of Care: the meaning of "Palliative"

It is important to differentiate:

- **palliative care principles** which apply to all care, whatever the disease suffered by a patient
- **palliative techniques or therapies** include medical and surgical therapies or procedures (e.g. stenting, paracentesis, internal fixation of fractures and radiotherapy) that are employed to palliate symptoms and ease suffering but are only a small part of the spectrum of care known as palliative care
- **specialist palliative care** in some countries is practised in units operated exclusively for palliative care by doctors and nurses who are accredited specialists in palliative care. Whether such specialisation is important or essential is something that can only be debated in the context of national needs and resources.

## Frequently asked questions

**Is Palliative Care the same as Hospice Care?**

**Is Palliative Care the same as Hospice Care?**
Yes, the principles are the same.

- hospice means different things in different countries - it is variously used to refer to a philosophy of care, to the buildings where it is practised, to care offered by unpaid volunteers, or to care in the final days of life
- it is better to adopt and use the term palliative care, a term understood by and used by health care professionals

**Should a Palliative Care service provide care for patients with chronic diseases?**
No, although their care is important.

- patients with chronic conditions such as rheumatoid arthritis, degenerative diseases, diabetes mellitus and similar conditions usually do not have active, progressive, far-advanced disease
- nevertheless, **many of the principles of palliative care are appropriate to the management of patients with chronic diseases**

**Should a Palliative Care service provide care for patients with incurable diseases?**
No, although their care is important.

- as with patients with chronic diseases, these patients usually do not have active, progressive, far-advanced disease
- nevertheless, **many of the principles of palliative care are appropriate to the management of patients with incurable diseases**

**Should a Palliative Care service provide care for patients incapacitated by their not-life-threatening disease (eg stroke, post trauma disability)?**
No, although their care is important.

- patients incapacitated by psychiatric illness, cerebrovascular accidents, trauma, dementia and the like deserve special care but they usually do not have active, progressive, far-advanced disease
- nevertheless, **many of the principles of palliative care are appropriate to the management of patients incapacitated by their disease**

**Should a Palliative Care service provide care for the elderly?**
No, although their care is important.

- many patients needing palliative care are elderly but they need palliative care because of the underlying disease from which they are suffering, not because of their age
- nevertheless, **many of the principles of palliative care are appropriate to the management of the elderly** /geriatric medicine

**Is Palliative Care just Terminal Care / Care of the Dying?**
No.

- the provision of high quality care during the final days and hours of life is an important part of palliative care
- palliative care should be initiated when the patient becomes symptomatic of their active, progressive, far-advanced disease and should **never be withheld until such time as all treatment alternatives for the underlying disease have been exhausted**
- palliative care may be appropriate long before the terminal phase.

**Should Palliative Care stay separate from mainstream medicine?**
No.

- palliative care originated because of the belief that terminally ill patients were not receiving optimal care and there was for a long time mutual distrust between the practitioners of palliative care and orthodox medicine
- modern palliative care should be integrated into mainstream medicine
- it provides active and holistic care that is complementary to the active treatment of the underlying disease
- it will foster palliative care skills for other health care professionals, particularly better pain and symptom control and appreciation of the psychosocial aspects of care

**Is Palliative Care not just 'old-fashioned' care?**
No.

- palliative care was originally separate from mainstream medicine, and was frequently practised by very caring individuals who knew little about medicine
- modern palliative care is more integrated with other health care systems and calls for highly trained doctors and nurses, competent in a range of medical disciplines including internal medicine, pharmacology, communications skills, oncology and psychotherapy

**Is Palliative Care what you do when "nothing more can be done"?**
No.

- no patient should ever be told "there is nothing more that can be done"—it is never true and may be seen as abandonment of care
- it may be permissible to say there is no treatment available to stop the progression of the underlying disease, but it is **always** possible to provide care and good symptom control.

**Does Palliative Care include euthanasia and physician-assisted suicide?**
No.

- a request for euthanasia or assisted suicide is usually a plea for better care or evidence that more care and support are needed by relatives.
- depression and psychosocial problems are frequent in patients making requests and both can respond to appropriate care
- unrelieved or intolerable physical or psychosocial suffering should be infrequent if patients have access to modern inter-professional palliative care
- terminally ill patients suffering intractable symptoms can be treated by sedation; this does not constitute euthanasia or physician-assisted suicide

**Is a palliative care service really a pain service and its doctors' pain specialists?**
No.

- Most but not all patients needing palliative care have pain of one sort of another but there are usually many other reasons for their distress. Focusing on pain to the exclusion of the others does not help the patient
- Palliative medicine doctors have all had advanced training in pain management but not necessarily in invasive measures (though these are less frequently used in modern palliative care.). Their training has embraced all aspects of suffering – physical, psychosocial and spiritual –but their certification is in palliative medicine, not chronic pain management.

## The need for Palliative Care:

- fifty-two million people die each year
- it is estimated that tens of millions of people die with unrelieved suffering
- about five million people die of cancer each year, to which can be added the numbers of patients dying with AIDS and other diseases who might benefit from palliative care
- that many people die with unnecessary or untreated suffering has been well documented in many studies and published in hundreds of scientific papers and reports
- in developed and developing countries alike, people are living and dying
  - in unnecessary, unrelieved pain
  - with uncontrolled but controllable physical symptoms
  - with unresolved psychosocial and spiritual problems
  - in fear and loneliness, often feeling unwanted burdens.
- this is the suffering that could be helped or prevented with palliative care
- the World Health Organisation (1990) and the Barcelona (1996) declarations both called for palliative care to be to be included in every country's health services
- **the relief of suffering is an ethical imperative**
  - every patient with an active, progressive, far-advanced illness has a right to palliative care
  - every doctor and nurse has a responsibility to employ the principles of palliative care in the care of these patients
  - every patient has the right to die in a place of their choice

## The Goals of Palliative Care

For patients with active, progressive, far-advanced disease, the goals of palliative care are:

- to provide relief from pain and other physical symptoms
- to maximise the quality of life
- to provide psychosocial and spiritual care
- to provide support to help the family during the patient's illness and in their subsequent bereavement.

## Palliative Care and Suffering: Inter professional Care

**Suffering** may be defined as the distress associated with events that threaten the intactness or wholeness of the person. In clinical practice, it is helpful to have a simple**classification of the causes of suffering**, so that the complex problems presented by patients can be disentangled, in order to provide comprehensive palliation and relief of suffering:

- Pain
- Other physical symptoms
- Psychological
- Social
- Cultural
- Spiritual

The **components of palliative care**, or the aspects of care and treatment that need to be addressed, follow logically from the causes of suffering. Each has to be addressed in the provision of comprehensive palliative care, making a multidisciplinary team approach to care a necessity.
Treatment of **pain and physical symptoms are addressed first** because it is not possible to deal with the psychosocial aspects of care if the patient has unrelieved pain or other distressing physical symptoms.
The **various causes of suffering are interdependent** and unrecognised or unresolved problems relating to one cause may cause or exacerbate other aspects of suffering
Pain and psychological suffering area inter-related

- **Unrelieved pain can cause or aggravate psychosocial problems** These psychosocial components of suffering cannot be treated successfully until the pain is relieved
- **Pain may be aggravated by unrecognised or untreated psychosocial problems.** No amount of well prescribed analgesia will relieve the patient's pain until the psychosocial problems are addressed

**A multidisciplinary/team approach to assessment and treatment is mandatory**

- Failure to do this often results in unrelieved pain and unrelieved psychosocial suffering. No one professional can deal with the many problems encountered in palliative care. An integrated team is essential.

## Multidisciplinary and Inter professional Teams

Successful palliative care requires attention to all aspects of a patient's suffering. This requires input or assistance from a range of **medical, nursing and allied health personnel**—a multidisciplinary approach.

Established palliative care services work as a **multidisciplinary** or **inter professional team**

- **multidisciplinary** is the term that used to be applied to palliative care teams, but if the individuals work independently and there are no regular team meetings, patient care may become fragmented and conflicting information given to patients and families
- **inter professional** is the term now used for teams that meet on a regular basis to discuss patient care and develop a unified plan of management for each patient, and provide support for other members of the team
- Where palliative care services have not yet been established, it is important for the few professionals providing such care to work as a team, meeting regularly, planning and reviewing care, and supporting each other.

**The patient** may be considered a 'member' of the team (although they do not participate in team meetings), as all treatment must be with their consent, understanding and in accordance with their wishes.
**The members of the patient's family** can be considered 'members', as they have an important role in the patient's overall care and their opinions should be included when formulating a plan of management, then fully explained to them.
**Volunteers** play an important role in many palliative care services. They receive no pay but may be offered expenses. They work in reception, coffee rooms, library, appeals office, flower arranging, Day Unit, transport, charity shops but in most units do not perform 'hand-on' role with patients. They work under the direction of a Volunteer Service Manager, a salaried member of the staff.

**The ideal core multidisciplinary clinical team consists of:**

- Physician(s)
- Nurses (for both in-patient care and community care)
- Social Worker
- Physiotherapist
- Occupational Therapist
- Chaplain or Pastoral care worker

**Very useful, but not essential, are:**

- Clinical Psychologist (or visiting liaison psychiatrist)
- Clinical pharmacist
- Music and/or Art Therapist

More on staffing can be found in ***Getting Started*** (on this IAHPC website)

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